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Exploring ambivalent oxygen technologies-people-world relations through the lens of postphenomenology[1]

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Abstract

Technologies for medicinal oxygen delivery at home are increasingly part of the global health technology landscape in the face of rising rates chronic lung and heart diseases. From the mere notion of harvesting and privatising oxygen from the atmosphere, to its status as both dangerous and therapeutic, and finally to its capacity to both extend and limit life, oxygen as therapy materializes its status as an ambivalent object in global health. This analysis of ethnographic material from Uruguay and South Africa on the experience of home oxygen therapy is guided by philosopher Don Ihde's postphenomenology – a pragmatic philosophical approach for analyzing the relationships between humans and technologies. Participants related to their oxygen devices as limiting-enablers, as markers of illness and measures of recovery and as precious and limited resources. Oxygen was materialized in many forms, each with their own characteristics shaping

[1] A Spanish version of this accepted manuscript is available at http://dro.dur.ac.uk/

the ‘amplification/reduction’ character of the relationship as well as the degree to which the devices became ‘transparent’ to their users. Ihde’s four types of human-technology relations - embodiment, hermeneutic, alterity and background relations – are at play in the multistability of oxygen. Importantly, the lack of technological ‘transparency’, in Ihde’s sense of the term, reflects not only the materiality of oxygen but inequality too. While postphenomenology adds a productive material and technological flavor to phenomenology, I argue that a critical postphenomenology is needed to engage with the political-economy of human-oxygen technology relations.

Keywords

Ethnography, Political-Economy, Postphenomenology, South Africa, Uruguay, Oxygen Technology

Introduction

An elusive gas made material

The commodification of oxygen for therapeutic use goes right back to its discovery in 1775 (Jackson, 2007) and since the mid-20th century innovative technologies have facilitated its entry into the intimate space of the home. Fibrosis, rare lung diseases, advanced heart disease, and, most commonly, chronic obstructive pulmonary disease (COPD) can all lead to chronic hypoxia (oxygen levels in the blood below 90 or 92%) which may require the long-term use of supplemental oxygen. In COPD, oxygen is the only treatment proven to prolong life if used at least 15 hours a day, primarily by preventing *cor pulmonale* (enlargement of the right heart ventricle) (Stoller et al., 2010). As the prevalence of chronic lung diseases continues to rise, so too has cost (Diaz Lobato et al., 2015). In light of this, the provision of home oxygen therapy has been described as a project of 'Funding the Unfundable' (Stafinski et al., 2010).

Home oxygen therapy is an ambiguous technology in global health in three ways. Firstly, it commodifies and makes visible something that for so long in human history was out-of-sight and misunderstood (Jackson, 2007) and is still taken for granted today. The act of harvesting and selling oxygen from the atmosphere is itself ambiguous (who owns the oxygen in the air?) (Thornes and Randall, 2007). Secondly, rising concerns about air quality have started to challenge a view that air (and therefore oxygen) is perhaps not the infinite renewable resource we take it to be (Muindi et al., 2014). Already we are hearing of bottled oxygen being sold at convenience stores in Japan (Noriko, 2006), and fresh Scottish country air being sold in China (McKenzie, 2016). Furthermore, oxygen's role in combustion makes this life-giving gas also a dangerous one. Lastly, while its invisibility makes oxygen 'easy to forget about', when commodified it takes on an array of material forms with distinct implications. The forms and

these implications for the ways in which people and oxygen technologies relate are the topic of this paper.

A Postphenomenology of Oxygen Therapy

In order to investigate human-oxygen technology relations I draw on the pragmatic, tangible tools and concepts of postphenomenology proposed by philosopher Don Ihde (Ihde, 1990, 2015). Postphenomenology is a pragmatic philosophical approach for reflecting explicitly on how experience of being in the world for humans is, and has likely always been, mediated by some kind of technology, material artefact, or thing beyond, or in addition to the human body (Ihde, 2015). For anthropological work, "Ihde brings to these reflections a much greater awareness of the role of technology in shaping and constituting the human being" (Weiss (2008:5). Technologies like oxygen therapy shape life-worlds - i.e. the "taken for-granted 'common-sense reality' of the social world as it is lived by ordinary individuals" (Harrington, 2006: 341). Postphenomenology emphasizes a reorientation to the material in human experience compared to its predecessor, phenomenology. Rosenberger and Verbeek (2015) argue that the interpretation of phenomenology as the science of describing 'things as they are' has tended to include a view that technology and science distance and alienate us from reality as well as narrow our approach to reality. Postphenomenologists do not take this view and rather emphasize how technologies *mediate* rather than *alienate.*

Ihde's (1990) postphenomenology includes an extensive toolkit of concepts. The notion of multistability posited by Ihde is a response to the question "how is technology both something we design and use for our own purposes, and also something that influences, restricts, leads, inclines or controls us?" (Rosenberger & Verbeek, 2015; 26). Multistability refers to the way that any given technology can have multiple uses, meanings, interpretations and relations with its

human users, though the range of 'stabilities' (i.e. 'variations') will be constrained by the very materiality of the technology (Rosenberger & Verbeek, 2015). Here I consider how different oxygen-delivery devices support multiple experientially stable relations by drawing on the four types of human-technology-world relations and mediation conceptualized by Ihde - hermeneutic, alterity, background and embodiment - as well as other tools in the postphenomenological toolkit. Hermeneutic relations are those where the person relates to some form of sensorial read-out produced by the technology (e.g. a step counting watch). Alterity relations refers to technologies that take on a human-like quality mimicking a person-to-person interaction (e.g. speaking GPS devices). Background relations describe the kinds of relations we have with technologies that are not at the front and centre of our day-to-day activities or, 'off to the side' (e.g. air conditioning) (Rosenberg and Verbeek, 2015: 19). Embodiment relations imply that the "user's experience is reshaped through the device, with the device itself in some ways taken into the user's bodily awareness" – eyeglasses being the classic example (Rosenberg and Verbeek, 2015: 14). These technologies, Ihde (1990) says, can be more or less 'transparent', meaning fade into the background of the user's awareness. Relations between humans and technologies can also take on an amplification/reduction structure meaning that experience of the world may be magnified and/or amplified but the trade-off may be "a decrease of a sense, or area of focus, or layer of context" (Rosenberger and Verbeek, 2015: 16). Ihde also distinguishes between the individual and the social bodies with the concepts Body 1 - "the body that we are in an embodied, experiential and emotive sense" and Body 2 - the "social and cultural body, the body that we are invited or pushed to shape according to cultural fashion, expectation, rules, and norms" (Van Den Eede, 2015: 147).

The analysis presented is an example of what Whyte (2015) terms "practical multistability" in which "variational analyses are run across a set of examples" emerging from different peoples' first-hand experiences (175). Authors have been applying such approaches to study the contextual relations between humans and a range of technologies including a robotic pet made in Japan to assist the elderly (Hasse, 2013), self-tracking devices (van den Eede, 2015), and obstetric ultrasound (Verbeek, 2008), to name but a few. Postphenomenology overlaps with, and differs from, other theoretical approaches to human-technology relations (e.g. actor-network theory, cyborgism) but space precludes comparing these. Rather, in this article I demonstrate the application of postphenomenology to a comparative ethnographic case study and appraise some of the advantages and limitations of the theory. In this case while the postphenomenological toolkit resonated with the data and was helpful, I also argue that there is a need for critical postphenomenology, meaning the study of human-technology relations that takes political economy more clearly into account.

Methodology

Study design

This paper draws on data generated during two ethnographic studies. The first (2010-2011) included 13 months of ethnographic fieldwork in two Uruguayan cities: Montevideo and Tacuarembó. The second (2016-2017) included seven months of fieldwork in Cape Town, South Africa (SA), and five months of fieldwork in Montevideo, Uruguay (UY). Both studies were shaped theoretically and methodologically by political-economy (Baer et al., 2003) phenomenology (Jackson, 1996; Csordas, 1994) and postphenomenology (Ihde 1990, 2015; Rosenberg and Verbeek, 2015).

Settings

At the time of this study, Uruguay was a high-income country of 3.4 million people with an increasingly polarising, but large middle class. South Africa was an upper middle-income country of 52 million people with persistently stark differences between rich and poor, especially along racial lines. Figure 1 shows the eight hospitals where participant observation was carried-out in the three cities across both countries. Both countries have split public-private health systems with reforms under way to improve universal access to health care and narrow the gap between private and public. Uruguay's reform started in 2005 and South Africa's in 2014. Private healthcare primarily takes the form of medical aid (third party health insurance) in South Africa, and direct membership of a private healthcare provider in Uruguay (for profit, or cooperative not-for-profit *mutualistas*). Part of the healthcare reform in Uruguay was the creation of FONASA – a national health fund to which all workers and pensioners contribute. In turn, contributors can elect to affiliate to a state institution administered by ASSE (Administration of State Health Services within the Ministry of Health), to a *mutualista* or to a for-profit institution. FONASA covers the full premium for state and *mutualista* institutions, but for-profit private hospitals are only partially covered by the fund. Though the premium for a *mutualista* is paid in full by FONASA, co-pay fees are charged by most *mutualistas* for appointments, tests and medications (including oxygen in some cases).

Methods

Both studies employed a combination of interviews and participant observation to explore the perspectives and experiences of people on oxygen, families, health professionals and policy-makers. This paper focuses predominantly on oxygen users and oxygen nurses who visited them at home. Participant observation was carried-out in outpatient respiratory clinics in hospitals

(Figure 1) and out with oxygen nurses on their home visits to patients which is how I met people on home oxygen therapy. Participation in the study ranged from agreeing for me to observe the appointment, to doing an oral waiting room questionnaire, to being informally interviewed while waiting for services (e.g. pharmacy or x-rays), to being interviewed at home. Fieldwork was carried out in Spanish in Uruguay and in English in South Africa. Most of the participants in South Africa were Afrikaans first-language speakers but all were fluent in English.

[insert Figure 1 about here]

Participants

The 42 participants represented in Figures 2 and 3 are those I had extensive conversations with around their experience of oxygen therapy. Four were not visited at home, either because of safety, being ill, or being unable to establish a convenient time. All participants were white or mixed-race. That I did not observe any appointments with black patients on oxygen therapy is probably due to a combination of factors (e.g. catchment areas of included hospitals having smaller black populations, barriers in accessing tertiary level care, and possibly lower rates of smoking).

[insert Figure 2 about here]

[insert Figure 3 about here]

Analysis

All data was stored and coded using NVivo11 qualitative data analysis software (QSR International, 2015). Analysis occurred in three stages. Firstly, prior to Study 2 all data pertaining to the 13 participants on oxygen in Study 1 were re-analysed with the following

question in mind "what kinds of relations exist between people and oxygen." The themes presented here emerged in preliminary form from this first analysis. Data from the second study confirmed that these themes resonated across contexts and contributed rich data that broadened the scope, depth and complexity of the themes. The third stage was to conduct a postphenomenological variational analysis (Rosenberger & Verbeek, 2015) in which the data supporting each theme was compared and contrasted using the technology as the pivot for the analysis (see Whyte 2015 for a discussion of the importance of 'pivots' for postphenomenology). Within each theme the type of technologies the individuals had access to is emphasized to uncover how the material characteristics of those variations mediated experience differently.

Findings – Ways of Relating

A myriad of materialities and intersecting devices

Oxygen was materialized in very different kinds of devices. Oxygen cylinders (Figure 4) are made of steel (heavier) or aluminium (lighter) and are filled with pressurized gaseous oxygen measured in cubic meters. Liquid oxygen (Figure 5) came in barrel-like tanks on wheels with refillable portable devices that could be docked into the mother-tank to be refilled (Figure 6). Oxygen concentrators are electric devices that suck in room air and through a series of compressors and filters (Figure 7) remove other gases, thus 'concentrating' the oxygen from room and outdoor air. They come in stationary form for home use (Figure 8), and portable form for ambulatory use (Figure 9 and 10). Though these oxygen devices may appear at first glance to be singular entities, they are in fact a composite of multiple devices including, depending on the device, pressure gauges, flow meters, regulators, nasal canula or masks, leads and extension tubing, humidifier bottles, and removable filters (some of these can be seen in Figures 4-10). A concentrator also typically included an internal clock that counted how many hours it had been

turned on for (seen in Figure 7). Two other technologies were virtually inseparable from the oxygen needs of most participants: electricity and oximeters. Oximeters are small devices that clip onto a finger and through red and infra-red light calculate heart rate and an estimate of oxygen saturation in the blood.

These neutral descriptions of the technologies that fall under the bracket 'oxygen' may give us a sense of the thing, but their ontological mutlistabilities are revealed only once we look at how they are used and how they shape peoples' lives in different contexts (Borgmann, 2006). Doing so revealed three 'ways of relating' to oxygen: as a limiting enabler – dependence and independence, as markers of illness and measures of recovery, and as precious and limited resources.

[insert Figure 4 about here]

[insert Figure 5 about here]

[insert Figure 6 about here]

[insert Figure 7 about here]

[insert Figure 8 about here]

[insert Figure 9 about here]

[insert Figure 10 about here]

A limiting enabler – Dependence and Independence

Jose (UY) was suffering from two very advanced lung diseases and had been using oxygen 24 hours a day for years. He had entered into an embodiment relation with his oxygen devices where he and they were inseparable. He was one of only two participants who had the

most comprehensive coverage for his oxygen through a third-party insurance company. The company fully covered the cost of a concentrator at home and a portable concentrator. He was never without at least one of his devices. For him, breathing comfortably was inseparable from wearing the canula, and inhaling the oxygen delivered to him by his concentrators. This can be understood as an 'embodiment relation' in that the oxygen was "a transformative mediation of the bodily-perceptual relationship between the user and the world" (Rosenberger & Verbeek, 2015;14). Embodiment of oxygen technology in this sense equated to a total dependence on them. Jose's wife explained the extent of his dependence, which she framed as psychological:

> "If the power goes out or if he's without oxygen for even just a minute he gets very anxious and panics. The oxygen, the doctor told us, is a treatment, it's like a medication. If he uses it 24 hours a day, then even better, but he doesn't need it to be able to breathe. He even showers with oxygen! He is psychologically dependent on oxygen."

When she says, "he doesn't need it to be able to breathe" what she means is that supplemental oxygen is not a respirator - it does not do the job of inhalation and exhalation for the person. However, experientially and sensorially many with advanced disease felt they could not breathe without it – thus they depended on it. Comfortable breath was a technologically-mediated one, meaning that going without was abnormal. When nothing interrupted the flow of oxygen, it could fade into the background once one got used to the huffing and puffing and rumbling noise of the concentrator and the sensation of the canula or mask. However, the transparency of the technology was shattered quickly when there was an interruption in the flow of oxygen, whether that was because of someone accidentally standing on the tubing extension running down the hallway, the machine malfunctioning, or the power going out thus cutting out the supply of electricity on which the machine depends (more on electricity later). For Jose there

was no doubt that oxygen technology enabled him to do more because with supplemental oxygen he was able to keep his oxygen levels higher while being physically active, thus reducing the disabling effects of extreme shortness of breath. While there was an amplification/reduction element certainly at play, his access to a portable concentrator enabled him to leave the house easily, he continued to drive (he could plug his device into the cigarette lighter), and could even go on holiday with his family.

Dependence like Jose's generally grew over time, with most participants starting off needing to use their oxygen the prescribed 15 hours a day, to eventually needing it 24 hours a day. When I met Isabel (UY), she was somewhere between resisting and accepting. I met her out on one of my afternoons with the oxygen nurses. We found Isabel hooked up to her oxygen cylinder in bed. She told us that she tries not to use the oxygen very much because even though the doctor on the ward told her it is a myth that one can become addicted to oxygen, she does not believe this is myth. In our interview a couple weeks later she explained that she feels it is addictive because when she has been using it for a while and then takes it off, she finds it more difficult to breathe than before she had put the oxygen on. She did not use oxygen the entire two-hour interview and said she was fearful of becoming 'oxygen-dependent'. Her sense of herself as not oxygen-dependent was also reinforced by the fact that her prescription was for only eight hours a day. Her particular *mutualista* had been struggling to get doctors to prescribe oxygen according to the guidelines, which is that oxygen should be prescribed for a minimum of 15 hours a day to treat chronic hypoxemia and reduce the risk of developing heart disease. Once oxygen technology is embodied as the new normal or comfortable breath, going without is challenging – hence the feeling of addiction. In this case an embodiment relation implies dependence (or addiction for some) and it is precisely this relationship that Isabel was resisting

entering into. Something else was contributing to Isabel's resistance however. The material form her oxygen took was that of a huge six cubic meter oxygen cylinder weighing over 60kg. The tank was difficult and dangerous to move because it could seriously injure someone if it toppled over. Unlike a concentrator that was on wheels and could be moved to another part of the house with an electric socket, her oxygen cylinder could not, which meant that when she used it she was confined to her room. Her house was big and the tubing from her tank to her cannula was not long enough to enable her to walk to the bathroom with her oxygen on. Increasing the use of oxygen involves her world reducing more and more to the confines of the four walls of her room. Though she may have the option of switching to a concentrator, her *mutualista* did not provide portable concentrators, so unless she could pay for one out of her own pocket she was likely to become more and more homebound. For now, the embodiment of the technology and all it implied would be resisted.

Whether oxygen technology was associated with a loss or a gain of independence depended not only on the type of technology but also on the circumstance it was introduced into. Mohamed (SA) had been on oxygen for close to four years, 16 hours a day. Before starting oxygen he was skin and bones in his early 50s and was so weak he was unable to walk to the toilet and had to relieve himself in a bedpan which his daughters and wife assisted him with. Part of his illness experience was finding a new spirituality and he converted to Islam. He explained that the doctors did a test and found that "the oxygen in the blood was too weak" so he needed oxygen to "keep up strength". He framed the oxygen as strengthening his weak blood. As his blood strengthened, so did he, and at the time of meeting him he was surprisingly agile, had put on weight and was able to get around the house though he still needed help tying shoes, washing his hair or brushing his teeth. He lived in a small two bedroom house with his wife, three

children and four grandchildren. He accepted that his life now was mostly confined to his home and felt this was Allah's way of testing him for having abused his body so badly in his youth. Mohammed embodied his oxygen as did Jose but with an important difference. For Mohammed, oxygen came from Allah and he had a ritual of holding up his nasal cannula each morning and praying to God. His relationship with oxygen was therefore not just embodied, but the technology mediated an embodied relationship with his God.

Mohammed is homebound because his state healthcare provider does not offer portable devices, rather it provides him with a concentrator and a back-up cylinder to use strictly in the case of a power outage. These back-up cylinders are not defined as 'portable' devices, they are still close to a meter tall and are too heavy to carry. Nevertheless, patients like Mohammed arrived at the clinics with these tanks resting on the foot pedals of the wheelchair between their legs, having popped them in the back of the car to make it to the hospital. Mohammed also shared a story of being picked-up by a friend and loading the cylinder into the car to head to the mall. At the mall they popped the cylinder into a shopping cart which he pushed around with him - a rare and delightful moment of getting out of the house. Here the non-portable device, becomes portable, finding a new stability one would not expect. Where there is a will for independence, there is a way, especially if one has the guts to bend the rules, and hit the streets with what must have been a fairly unusual sight. However, we should not mistake this rule-bending as an ideal situation because of the risks inherent in handling a high pressurized tank, and the risk of using up a back-up cylinder that might be needed in a power failure.

Jose, Isabel and Mohammed's experiences show that independence and dependence are two stabilities – stable patterns of human-technology relations. The dual effect of dependence/limiting and independence/enabling can be understood through Ihde's concept of

amplification and reduction. Here body 1 – the individual body, intersects with body 2 – the social body. Oxygen technology amplifies life, by extending it, enabling greater physical activity (otherwise hindered by fatigue and breathlessness) and by relieving the anxiety associated with shortness of breath, making space for new forms of experience despite illness. At the same time, it engenders a reduction in social space so that the new forms of experience that it enables are actually difficult to achieve practically. This was especially the case for the majority without portable technology, but by looking more closely multiple stabilities appear. While a concentrator and a cylinder were both stationary, in fact the concentrators were on wheels and could be moved to different areas of a house. How much one can move from the device depends not only on the length of the tubing but on the size and layout of the house. And, what may be defined as a back-up and not a portable cylinder, can in fact become portable if you can find the people and the means to give it mobility. Dependence and independence were clearly two multi-stable outcomes of an oxygen technology mediated world.

Markers of illness and measures of recovery

Having to use oxygen while hospitalized was common for most people with serious lung disease, but having to take the technology home with you was not. To do so was strongly symbolic of advancing illness both to oneself and to others. In day to day life outside the hospital different signs were read from the oxygen devices for clues as to how one was doing. Am I/is she getting worse? Am I/is she improving? Am I/is he having an attack? Am I/is he OK? And, particularly from the healthcare professional perspective, is he/she using the technology as prescribed? Clues were also read into how the technology was doing, as patients were expected to care for them too. This was very much Ihde's Body 2 exemplified.

Time was a key marker of illness and measure of recovery. For health professionals, oxygen therapy is proven to prolong life if used at least 15 hours a day and so it was important that patients used it for at least that amount of time. For some patients, friends and families, this was not entirely well understood and I observed a number of instances of equating using less with recovering and getting better. Time could be perceived and read-out of the technologies in different ways and Rosenberger & Verbeek (2015) are keen to remind us that readouts are not only visual but any kind of output which can be perceived through any of the senses (e.g. hearing). These outputs varied according to the material form the oxygen took as well. Most concentrators had in-built clocks that counted the number of hours the machine had been on. This was used by oxygen nurses as a proxy for compliance as they could calculate how many hours the machine had been turned on since their last visit and calculate a rough estimate of how many hours the machine was running per day. Few patients were aware of these clocks which were usually tucked out of sight. They read their use in other ways, such as through reading their electricity usage on their meters or on the paper or electronic bills they received. They often also kept track, more or less, of how many hours they used by sticking to a schedule, e.g. using oxygen all night and until lunchtime, or starting from 4pm until the following morning, if they were not using it 24 hours a day. Florencia (UY) started oxygen after a life-threatening experience in hospital and was so weak she could barely speak when we first met. She was using oxygen 24 hours a day. Over my regular visits in the five months in 2011, I observed Florencia's relationship with her oxygen change. She began using it less.

> Fieldnote: Florencia removed her oxygen mask for around 45 minutes and was very proud of herself for this. "Ana (the young woman employed to stay with her during the day), is my witness today, because sometimes the daughters don't believe me when I tell

> them I haven't used the oxygen for a while", she said. Then her youngest daughter's husband came by and she said to him "Look, I haven't used the oxygen for 20 minutes". He gave her a congratulatory look. I asked her what she is hoping will happen. She said without hesitation that she wants to not have to use oxygen, to have to use it less and less.

Florencia's desire to use her oxygen less was reinforced by family who also read her reduced usage as a sign of her recovery. However, from a medical perspective, even though she might have felt capable of going without because she had recovered her strength and had less shortness of breath, she was still hypoxic and to protect her heart, and thus prolong her life, she should continue using it at least 15 hours a day. The other key factor here was that at first she only had a mask and no canula, and because she loved to talk, but hated to speak with her mask on, she was keen to remove it. Technological transparency could rarely be achieved through a face mask. For others who had the option of either a face mask or canula, everyone around them knew that if they wore the mask, this was a sign that they were really struggling to breathe.

For those participants who did not have concentrators but had either cylinders or liquid oxygen tanks, read-outs of oxygen usage came in the form of the cost of phone calls they had to make requesting a delivery. For health professionals the proxy for amount of oxygen being used came in the form of the bill received each month by the oxygen company charging them for each refill they had had to make. Users knew when to call by reading out the gauge on the cylinder, or by pressing a button on the liquid oxygen tank that lit up a scale of how much oxygen was left in the tank. They needed to keep a close eye on these readouts and to call before they ran out because delivery could take a day or two. They developed a close hermeneutic relationship to these readouts in order to maintain reassurance that there was still oxygen left to breath, and to avoid the relationship becoming one of panic that it would soon run out. This was a very

different type of relation to those using concentrators: these could not run out in the same way, although those with concentrators had to do more maintenance on their machines, and could run out of the power to run them (next section).

The use of a portable device, though enabling an amplification of experience by expanding one's geographical mobility, was also a very strong symbol of illness socially. Both Martin (UY), who was doing face to face networking for his children's business and Max (SA), who worked in the business sector, were concerned about the negative image it cast of them and their abilities. Martin's experience was the following "the neighbour is the one that is most judgmental. They say: 'look at him, he's going to die'." Max went to great effort and planning to avoid having to use his portable oxygen when going into a business meeting. Alje (SA) recounted his regret of not having prepared his colleagues before going into work with his portable oxygen. He saw the shock in their faces and since that experience had decided to go without it at work while he could still manage. Victoria (UY) had a particularly negative experience when she was out with her portable liquid oxygen *mochila* when a shopkeeper refused to serve her. In her interpretation they read the use of her oxygen as a sign that she had an infectious disease.

When it came to developing hermeneutic relations another oxygen device stood out – the oximeter. In South Africa nobody in the state sector in my study owned one, whereas in Uruguay many did as these were more in reach economically (approximately 25-50 USD). Taking an oximeter reading was part of most outpatient visits and home visits by oxygen nurses. A hermeneutic relationship developed between users and these devices as the read out, in the form of a percentage of oxygen concentration in the blood and heart rate, gave them a kind of window into their own bodies. Users took it as a measure of what was really happening inside the body to

which they could compare their own sensation of shortness of breath to. Max and Simon (UY) used oximeters avidly and had a lot to say about them. Max used his oximeter to compare what he was feeling with what he saw as reality.

> "If I come in from somewhere and I'm really gasping, and I need to put the mask on, it [the oximeter] confirms this is not bullshit, I really need this. I really am serious, 57-58, 60 [%]. It also confirms that high 60s, 68-70, I'm fine. I'm not panicky. I'm short of breath, but it's not a big deal."

There were rare occasions however when the numbers did not quite match up, like the time he expected a low reading because of "feeling not quite comfortable with my breathing" but it read 95%. Simon was a rare case of a person being weaned-off oxygen because his oxygen saturation levels improved after recovering from a serious acute exacerbation and completing a pulmonary rehabilitation programme. The weaning process initiated by his doctor first involved using oxygen only at night. Then he was prescribed a night oximeter monitor to confirm he was not desaturating while sleeping. He then stopped entirely – getting used to not having it before the machine would finally be taken away. When the company came to pick up the machine Simon was a bit anxious and he took his oximeter readings repeatedly. This kind of hermeneutic relationship was not necessarily seen as a good thing by all health professionals. One oxygen nurse in Cape Town did not recommend her patients to buy oximeters as in her experience her patients come to "nurse the device" and become unnecessarily worried about slight variations in their readings.

A precious and limited resource

In reviewing the ethnographic data with the question of how oxygen technologies and people relate in mind, the third way of relating identified was 'as precious and limited resources.' It is worth remembering that this study looked at people with lung disease who were at the tip of an iceberg, that is those who had reached tertiary level care, lived in urban areas and were generally accessing very good care for their illness despite limited resources in both systems. However, the situation is most certainly different for those in rural areas further away socially and geographically from tertiary level care. The experiences of Florencia and Marcelo (UY), both in Tacuarembó in 2010, gave some insight into what it is like when even a basic supply of home oxygen is not readily available. They were both members of a public hospital that only provided an irregular supply of oxygen cylinders. To compensate and avoid having to be hospitalised just for oxygen, both families had spent their meagre incomes purchasing full cylinders for 1000.00 pesos each (50 USD). Worse than the financial hardship was the emotional and physical strain of watching the gauge as they ran out of oxygen and having no other choice but to go to hospital. Eventually, ASSE did source concentrators for them, but at first without back-up cylinders. What this meant was that in the event of a power outage there would be no oxygen. Florencia's daughter recounted a particularly harrowing night:

> Julia (Florencia's daughter): It was my turn to sleep with mom the other night when we had those storms. I was thinking "Please, don't make the electricity go out," because of the oxygen machine. My mother was sat in her bed and she asked me "Is the power going to cut out?" and I told her "No, no Mom, the power won't cut out, relax". But I was thinking "What do we do if the power goes out?" I'd call the emergency service but with this rain? Take her out, take her to the hospital?

The most precious kind of oxygen was portable oxygen, whether a concentrator or liquid oxygen. Indeed, portable oxygen was a 'luxury' available only to 16 of the 42 participants, seven of whom paid for it out of their own pockets. Portable devices were not provided in the state sector in South Africa. In the state sector in Uruguay liquid oxygen tanks with a refillable portable tank were, but as the most expensive material form oxygen could take, it was prioritized for oxygen-dependent patients with mobile lifestyles, such as students, workers or those travelling to hospital regularly (e.g. for pulmonary rehabilitation). In the private sector in both countries, only the most comprehensive medical aids/third party insurance might include portable oxygen in their coverage. Alje's medical aid provided a home oxygen concentrator but not a portable one, so he decided to buy his own for 33,000 rand (2400 USD) from an oxygen company. In Uruguay, the health reform included the first list of services and medications that state-run institutions and *mutualistas* were under the obligation to provide (called PIAS) which included oxygen therapy. However, PIAS did not specify the device, so the interpretation in the private sector seemed to be that only 'home oxygen' i.e. stationary oxygen, was their obligation to provide, not portable oxygen. This was the case for Natalia (UY), so she decided to rent liquid oxygen with a portable device for 2000 pesos a month (70 USD) from her *mutualista*. Concentrators might seem like a good investment for someone having to pay out of pocket but there was a limit on how many litres per minute they could deliver (5 litres), so it could not be used by people needing a higher flow rate to keep their levels above 90% while active. Portable concentrators and portable liquid oxygen tanks both contain limited resources, in the former battery power, and in the latter oxygen itself. People using these devices planned their outings carefully so as to not run out, though almost all had had this happen or come close to happening before. When they arrived at the hospital, both in Uruguay and South Africa, staff were very

aware of the preciousness and limitedness of the resource and were quick to hook them onto hospital oxygen supplies, so they could conserve their own.

Silvio told me he was the first person in Uruguay to receive a portable liquid oxygen concentrator while he was on the transplant list. After he had a transplant he returned the machine because he no longer needed it. He told me the emotional story of how on one of his check-ups he got into the elevator with a woman carrying a portable liquid oxygen tank. He told her that he used to use a *mochila* like that one. She asked his name and when he responded she said "I know you, this used to be your machine". He recounted how in that moment tears came to his eyes, not only for his sense of helplessness in the face of this woman's suffering but also because that *mochilita* had been a part of him and to know it was with someone else moved him. Unfortunately for Silvio, when we met, eight years after his transplant, his condition had deteriorated, and he was back on oxygen. However, his *mutualista* did not provide portable oxygen, and because he was no longer on the transplant list, he could not get that part of him back. I expected to hear more stories exemplifying an alterity-type relationship with oxygen like this one – i.e. where the oxygen takes on a kind of personhood in itself, but Silvio was a rare example of this, despite observing efforts among some health professionals to instil a sense of personhood to the machine. A nurse in Cape Town in particular personified oxygen to help instil messages to patients about caring for their oxygen concentrators since they were both costly to buy and costly to repair. She used rhetoric of 'blowing your machine's nose' in reference to the patient's responsibility to clean the filter at the back of the machine. She would tell her patients that if the machine was to help them breathe, it needed to breathe too – hence cleaning the filter and keeping some clear space around it so it could access the room air it needed. Participants cared for the machines and for some it became 'part of them' while for others, it remained a

precious ‘other’ – the symbol of illness they wished independence from, but wanted close at hand.

For the 33 participants who had concentrators, electricity was the technology most inextricably linked to oxygen therapy. Even with the back-up cylinder, people could run out if power cuts were extensive. In 2015 for example, there were rolling black-outs (called ‘load shedding’) in Cape Town that had oxygen home nurses and technicians worked off their feet to deliver back-up cylinders to people running out of oxygen. In South Africa the system of ‘pay-as-you go’ electricity meters also meant that people could literally exhaust the electricity supply needed to run their machines. Gavin (SA) told me of how he sometimes had to ration his use of his concentrator if he was getting low on electricity and did not have the money to top it up. Uruguay did have a policy for discounting the cost of electricity for running a concentrator, but the policy was difficult to locate, not altogether well known, and required paperwork and time to make happen. Angel (UY), unaware of this policy, like Gavin, rationed the use of his concentrator because of the electricity cost. The contrasts and contradictions were palpable: while some participants who lived in informal settlements in both countries who stole electricity from the main lines and therefore had no concerns about running their concentrators, lower middle class private patients in Uruguay resisted the *mutualista*’s desire to switch them from cylinders to a concentrator because they said they could not afford the electricity bill. Electricity was a necessary infrastructure (Larkin, 2013) and thus a perfect example of what Ihde calls a background relation. However, just because it was ‘in the background’ of oxygen therapy did not mean it was transparent as in both contexts access to electricity could not be completely taken for granted.

Conclusion

The people I met living with oxygen technologies in the home related to the oxygen technologies in their lives as limiting-enablers, as markers of illness and measures of recovery, and as precious and limited resources. Some of these themes have emerged in similar ways in the phenomenological research on living with COPD (Bailey, 2004; Ek and Ternestedt, 2008; Ek et al., 2011; Kelly and O'Brien, 2015; Kelly et al., 2016; Ring and Danielson, 1997). However, it is not always clear what kind of oxygen participants in these studies are on and how this influences their experiences, since the technology itself is often glossed over. Revisiting the data from Study 1 and undertaking Study 2 with a postphenomenological lens helped bring the materiality of oxygen-dependency to the fore. Each device and the particular features of its materiality, when considered in context, could amplify or reduce experience, could limit or enable, could be read in some instances as a marker of illness or in others as a marker recovery. However, none of these technologies were simply randomly distributed. Economics is the omnipresent background relation underpinning these experiences. Phenomenological and patient-experience studies on oxygen-dependency have touched upon this only in passing, for example, by referring to participants who could not access or afford oxygen (O'Neill, 2002; Wilson et al.,2008). While Ihde's Body 1 and Body 2 captures the subjective and some of the social, it does not capture the political-economy of human-technology relations. Scheper-Hughes and Lock's (1987) notion of the three bodies goes that crucial step further by emphasizing the body politic as well as the individual body and the social body. Epistemologically, they equate the study of the individual body to phenomenology, the social body to structuralism and the body politic to post-structuralism. However, critical phenomenologists recognized the potential for phenomenology to focus too closely on the sentient body at the expense of seeing connections between individual

experience and the political-economy (Melançon, 2014; Reid, 1973, Willen, 2007). French (1994: 69) claims a space for the body politic within phenomenology, arguing that "even the most apparently subjective and personal of experiences – the experience of one's own body – is shaped in important ways by the relations of power and domination in which the body is involved." The human-technology relations described here are deeply shaped by layers of economics, from individual means to pay for or run such technologies, to country's health systems deciding what they can and cannot afford to provide, to private industry trying to run a profitable business.

Obviously producing oxygen and inventing new and better oxygen delivery devices takes financial resources, but what is less obvious are the profit margins in the oxygen industry. In Uruguay, ASSE is reported to have reduced the cost of medicinal oxygen from 3 to 0.42 USD per cubic litre by producing their own oxygen through concentrators. The director of medical technology in ASSE stated that by doing so the government had liberated itself from the high prices set by oxygen multinationals (Presidencia, 2012). It is clear that the cost of home oxygen therapy makes its various material manifestations more or less accessible at a global, population and individual level. Thus, finances are perhaps the greatest mediator of hypoxic peoples' experiences of their worlds. Therefore, there is a need for a critical postphenomenology to supplement the productive technological flavour postpheonomenology adds to the lived experience of people with oxygen therapy with a further mediator, the political-economy of who gets what, where and when.

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Figures

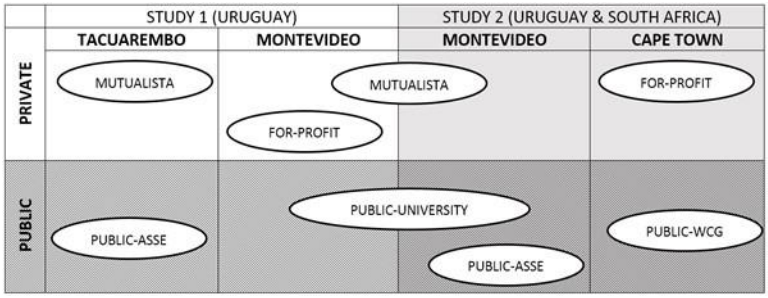

Figure 1. Hospitals where participant observation was conducted spread across countries, cities and public and private healthcare. ASSE = Administración de los Servicios de la Salud del Estado (Administration of State Health Services). WCG = Western Cape Government

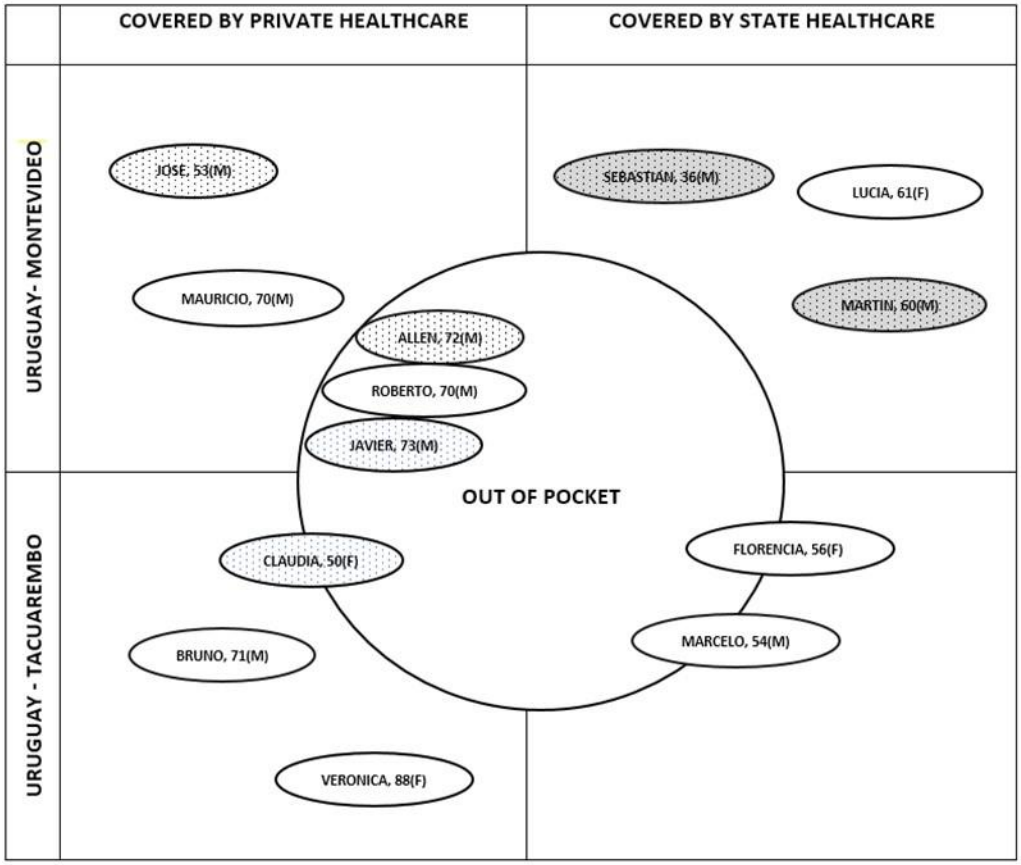

Figure 2. Study 1 participants visualized by location and by provision of their oxygen therapy. Those whose oval is dotted had portable oxygen device. Those whose dotted ovals are also grey had liquid oxygen. Those that overlap, or are within, the 'out-of-pocket' circle paid for all or some of their oxygen (or someone else did for them). The proximity to the 'out of pocket' circle for all those outside it is not significant. M: Male. F: Female.

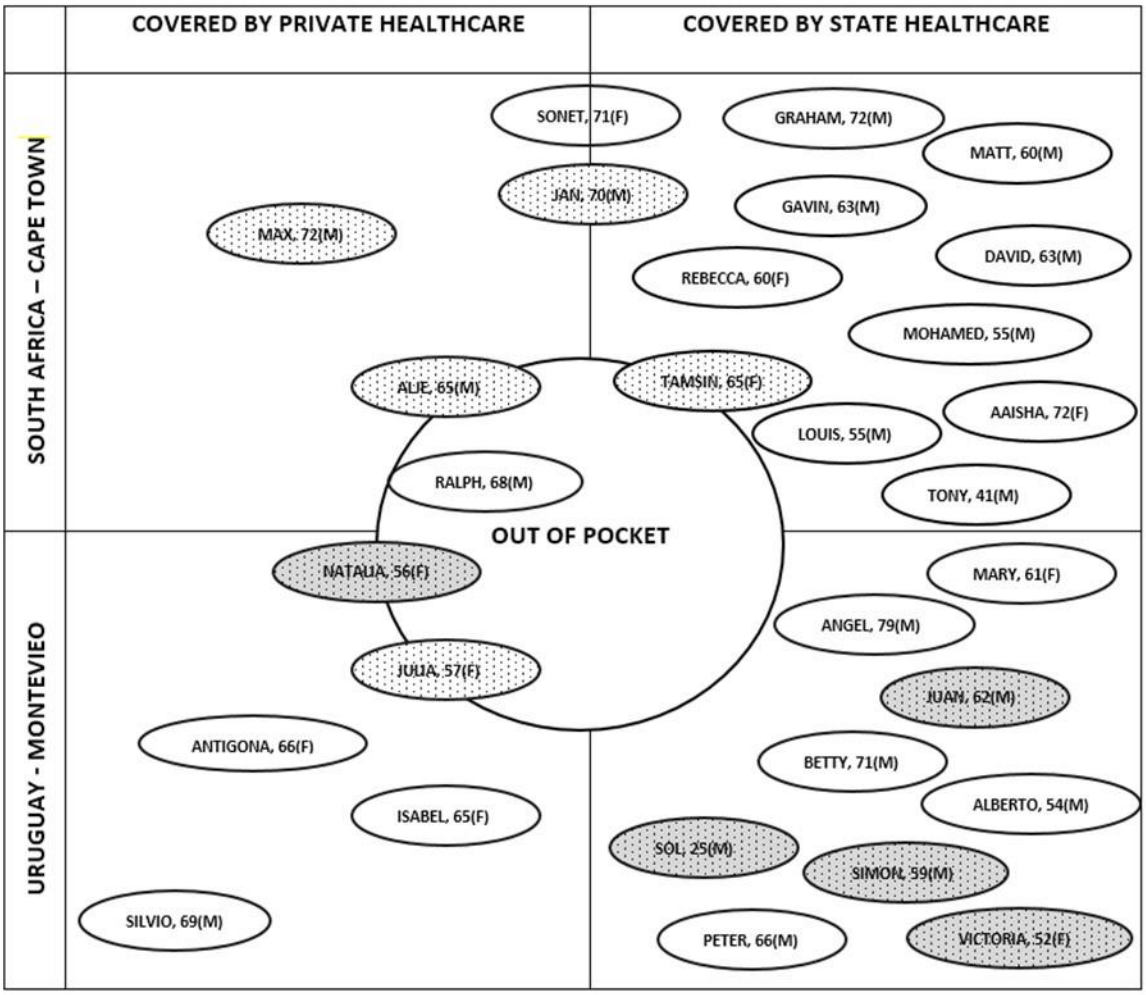

Figure 3. Study 2 participants visualized by location and by provision of their oxygen therapy. Those whose oval is dotted had portable oxygen device. Those whose dotted ovals are also grey had liquid oxygen. Those that overlap, or are within, the 'out-of-pocket' circle paid for all or some of their oxygen (or someone else did for them). The proximity to the 'out of pocket' circle for all those outside it is not significant. M: Male. F: Female. Sonet and Jan overlap public and private because they either were seen in the military health system which had partnerships with the private sector, or had a private medical aid that provided full coverage if services were obtained in public institutions.

Figure 4: An oxygen cylinder. Photo by author.

Figure 5: Liquid oxygen with docking station at the top for a portable tank. Photo by author.

Figure 6: The portable liquid oxygen tank being carried in a participant's backpack. Photo by author.

Figure 7: The inside of an oxygen concentrator. The clock counting running hours also visible.

Photo by author.

Figure 8: An electric stationary oxygen concentrator for home use. Photo by author.

Figure 9: A portable oxygen concentrator in purse-style carrying bag. Photo by author.

Figure 10: A portable oxygen concentrator in satchel-style carrying bag. Photo by author.